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Designing an mHealth application to bridge health disparities in Latina breast cancer survivors: a community-supported design approach

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ABSTRACT

Latina breast cancer patients in the USA report significantly worse cancer-related symptom burden and health-related quality of life than non-Hispanic whites. However, health literacy (e.g. knowledge about cancer, coping skills and communication) has been found to improve quality of life. In this paper, we present a case study of the methodology used to design Mi Guía (My Guide), a mobile application that aims to improve symptom burden and health-related quality of life among Hispanic women who have completed active treatment for breast cancer by increasing their health literacy. We developed a community-supported approach to building the application, which involved: (1) eliciting feedback from community leaders such as support group organizers and facilitators who are bilingual in Spanish and English, prioritize patients' preferences and best interests and have a unique knowledge of the women and their needs; (2) conducting a formal evaluation of design principles based on previous interaction design research and user responses; (3) incorporating feedback from potential future users. In this paper, we discuss our methodology, and the challenges and benefits of this approach. We believe that future studies that aim to develop mobile technologies for underserved populations may benefit from a community-supported approach to design.

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Introduction

Latinas experience lower breast cancer survival rates and later stages of breast cancer diagnosis compared to non-Hispanic whites (American Cancer Society

2014). Latinas also report significantly worse cancer-related symptom burden and health-related quality of life (HRQOL) than non-Hispanic whites during treatment and survivorship (Yanez, Thompson, and Stanton 2011; Luckett et al. 2011; Fu et al. 2009; Molina et al. 2013). Barriers to accessing and effectively engaging in health care, limited cancer information and beliefs about cancer are some factors that may contribute to these disparities (Kagawa-Singer et al. 2010; American Cancer Society 2014; Yanez, Thompson, and Stanton 2011). In addition, Latina women diagnosed with cancer may have difficulty gaining access to supportive and psychosocial services that can assist with symptom burden and HRQOL and face obstacles such as cost, lack of insurance coverage and time constraints (Byers et al. 2008; Kagawa-Singer et al. 2010). Despite this, very few randomized controlled trials have specifically targeted HRQOL among Hispanic women who have recently completed treatment for breast cancer. This is potentially a critical period to provide skills and tools to assist with the transition to survivorship (Fu et al. 2009).

The wide adoption of smartphone use among Hispanics in the USA provides a unique opportunity to implement psychosocial interventions that, through increasing health literacy, allow Hispanics to overcome some access to care barriers as well as time and logistical constraints of these populations (Lopez, Gonzalez-Barrera, and Patten 2013). Previous research has shown that delivering cancer-related knowledge, stress management, coping skills and communication, in a culturally appropriate intervention, can improve outcomes in the post-treatment survivorship phase (Penedo et al. 2007; Yanez, Thompson, and Stanton 2011; Yanez, Stanton, and Maly 2012). However, designing a mobile application for this population requires several important considerations. First, the content has to be provided in the appropriate language of the target population (Spanish and English) and despite the complexity of the material, the content has to be easy to browse and using a language that is clear and easy to follow. Second, although the design of most mobile application is developed based on the feedback of the users, the design process with Hispanic participants may be challenging. It is possible that Latinas may exhibit poor communication skills due to language barriers, and previous research suggests that they may have a bias towards responding affirmatively and in the least contentious way possible (Benson et al. 2016). Therefore, when designing a mobile solution, it may be appropriate to take into account feedback from stakeholders that live in their communities and whom patients trust.

The purpose of this paper is to describe the community-supported design approach we utilized to develop *Mi Guía* (My Guide), a mobile application that aims to improve symptom burden and HRQOL among Hispanic women completing active treatment for breast cancer through increasing health literacy. This community-supported approach involves: (1) obtaining ideas and feedback from community leaders such as support group organizers and facilitators, patients and medical professionals; (2) using students of human-computer

interaction to evaluate the extent to which the application conforms to design principles based on previous interaction design research; (3) validating our design with actual Latina breast cancer survivors. The design of My Guide strives to ensure an application that supports interaction design principles, while being culturally appropriate and helpful for Latina breast cancer survivors.

Designing mHealth applications for Hispanic patients

Computer-based health applications (eHealth) include a wide range of solutions, from standalone systems, web interfaces and mobile applications. This latter subset of applications is called mHealth. Mobile devices provide an ideal method for improving access to health information for low-income or rural families (Martin 2012). In addition, mobile devices are widespread among diverse populations within the USA, including Hispanics, which make them ideal tools for health care (2012).

Over the past decade, there has been a proliferation of mHealth applications that deliver evidence-based treatments for health management (Eysenbach and CONSORT-EHEALTH Group 2011; Leykin et al. 2012; Yanez et al. 2015). There is a need for patient support systems in mobile phones, particularly for cancer patients (Mirkovic, Kaufman, and Ruland 2014; Pandey et al. 2013). Given the ubiquity of mobile devices, researchers have suggested that delivering interventions via mobile applications has several benefits, such as cost saving and increasing in health literacy (Almarri and Bhatti 2015). mHealth platforms may be particularly relevant for Hispanic patients. In comparison to non-Hispanic whites, 11% more Hispanics look up health-related information using their mobile devices. Furthermore, 4% more women than men use their mobile devices to look up medical information (Fox and Duggan 2012).

Community-supported design

Since mHealth applications are growing in popularity, usability is becoming a significant concern when designing a mobile app, particularly when designing an mHealth application (Zapata et al. 2015). Mohr et al. (2014) approach the design phase of eHealth and mHealth applications paying special attention to the content ('what'), the purpose ('why') and the interactions ('how'), but allow the immediate stakeholders to provide feedback for the design. However, in the development of computer-based applications, user-centred design is fundamental (Norman and Draper 1986). Involving users throughout the entire design process ensures a more usable system once deployed. User-centred design has been adopted by many mHealth and eHealth development processes (Jibb et al. 2014; Cafazzo et al. 2012; McCurdie et al. 2012). Thus, during the design phase of eHealth applications, designers obtain feedback from a target population (e.g. Atkinson et al. 2009) or directly from patient focus groups (e.g. Steele Gray et al. 2014). Then, they validate their applications by testing them with the target

population. Some use mixed methods that involve interviewing some other stakeholders, like medical staff, in their capacity as users of the application (Gilbertson-White et al. 2016) or as a secondary source of information for the initial design phase (Van Velsen, Wentzel, and Van Gemert-Pijnen 2013). Finally, many developers base the content of their applications on previous literature and other secondary sources and conduct iterative user testing to improve their initial interface design (Fu et al. 2016).

De Vito Dabbs et al. (2009) discuss three user-centred design principles used to develop an mHealth tracking application: (1) Focus on the User and Tasks; (2) Measure Usability Empirically; (3) Design and Test Usability Iteratively. In the last phase of their research, a field study was conducted to determine if patients had an issue using the system independently. They were able to determine which features were used more often than other features and whether or not the application successfully prompted patients to report the study's main outcomes to their doctor.

Co-Design is another approach that has been adopted for health care applications. This process is analogous to participatory design (Kensing and Blomberg 1998), where end-users, as well as other stakeholders, are not only testers of technology, but participate actively in the design process, blurring the lines between designers and users (Sanders and Stappers 2008; Reay et al. 2017). Users now express themselves and participate directly and proactively in the design process (Frascara 2002). However, a participatory design approach implicitly assumes that the design propositions of every party are easy to interpret.

When designing applications for Hispanic patients, one must consider a few unique characteristics of these users. First, limited English proficiency can be an important obstacle for patients' understanding of physicians' instructions or reading materials about their condition (Wilson et al. 2005). In addition, Bender et al. (2001) warn about the importance of designing research instruments that reflect the perceptions of the research subjects rather than simply those of the investigators. For example, research shows that minority patients are less expressive and assertive with their doctors (Schouten and Meeuwesen 2006) and that this behaviour may stem from social desirability beliefs.

In particular, Hispanics exhibit these social desirability biases talking to clinicians or responding surveys (Hopwood et al. 2009). This extends to interactions with researchers as well. Hispanics exhibit a bias to 'yea-saying' (answering questions in the affirmative) greater than the general US population (Aday, Chiu, and Andersen 1980; Benson et al. 2016). Hispanic women may have trouble with survey questionnaires, commonly used to assess user experience. In an effort to be courteous, they may opt for the least contentious responses (Saint-Germain, Bassford, and Montano 1993). This phenomenon is also prevalent in interviews.

To overcome some of the limitations of designing for this population, our methodology merged aspects of participatory design and user-centred design, and added a strong community emphasis to create a *community-supported*

approach to design, whereby community leaders play a vital role in the design process. These leaders are part of the user's community and are trusted by the users. For these leaders, language is not a barrier and they know the unbiased patient's opinions. In addition, it is important that they have the patient's best interest at heart, but have no motivation to exhibit social desirability on their behalf.

In our community-supported approach, we carried out iterative usability tests with fewer participants, but the iterations also involved interviews with community leaders who have gained the confidence of the participants. We asked them to give feedback from two perspectives: the participants' and their own. The first perspective supplemented the feedback from the participants, and the second one provided valuable feedback on content and organization, as they are capable of prioritizing the content the participants need to know and care about.

The following section details our approach to design, which emphasized community and user input throughout the process.

Community-supported design process

The design of Mi Guía strived to ensure an application that respects interaction design principles, is culturally appropriate, and useful for Latina cancer survivors in terms of improving HRQOL. Accomplishing these overarching goals involved a process that iteratively refined a mock-up prototype, developed using Ninja-Mock (<https://ninemock.com/>), by (1) obtaining ideas and feedback from community leaders such as support group organizers and facilitators as well as medical professionals; (2) performing heuristic evaluations of design principles based on previous interaction design research; (3) obtaining feedback, suggestions and validations of the prototype's interactions with actual Latina breast cancer survivors within our target group.

It is important to note that the interactions with these stakeholders were not sequential, but the result of an iterative process that involved multiple sessions with the three groups of stakeholders.

Community-supported team: medical professionals and community leaders

Community leaders that support breast cancer patients and survivors have a unique knowledge of issues that affect breast cancer survivors. Throughout the design of Mi Guía, we consulted with two community leaders from not-for-profit organizations that provide support for breast cancer patients/survivors in our geographic area. One community leader was the programme manager for Latino community-based initiatives of a large urban cancer support centre, and the other was the founder of a smaller organization specially focused on breast cancer support for Latina patients. Both community leaders were bilingual Hispanics and one was a breast cancer survivor. Both leaders conduct support groups in their respective organizations. In addition, we included feedback of an

oncologist and a patient navigator from a large medical school in Chicago. The roles of these community leaders and medical professionals put them in a unique position of intimate knowledge of the patient's beliefs. We also included feedback from medical social scientists from two high research universities in Chicago. We held several meetings with all these medical professionals and community leaders where we brainstormed and discussed feedback from users. In addition, we held separate meetings with community leaders as well as meetings with medical social scientists throughout the design of *My Guide*. The feedback from these community leaders and cancer professionals was not only specific to design issues, but also covered content and delivery so that the application would resonate with the patients. These community leaders were able to articulate criticism and suggestions to a larger degree than the actual patients who participated in the design process.

Results from medical professionals' and community leaders' feedback

We started our design with our main section about breast cancer ('Breast Cancer Education'). However, after our meetings with community leaders, medical social scientists and patient navigators, and understanding the difficulties that our target population experiences in searching information (Bickmore et al. 2016), we designed sections where patients could look up information of interest quickly. Specifically, participants were able to search for: (1) symptoms they may be experiencing by tapping in the affected area of the body ('My Symptoms'); (2) information related to medications; (3) a list of resources such as support groups. In addition, the prototype contained an interactive section (Journal), where users could record their symptoms on a daily basis (see [Figure 1](#)). The application also had an icon to contact the experimenters.

Based on feedback from our community leaders, several modifications were adopted:

- (1) Our initial 'My Symptoms' section allowed tapping in any part of the body. However, our community leaders felt that patients may not feel comfortable clicking on private body parts when wanting to learn more about symptoms such as vaginal dryness or hardness of the skin in the chest. Moreover, community leaders expressed concern that end users may be uncomfortable clicking on the name of the body part. Therefore, our final version of the body included in the 'My Symptoms' section involved radio buttons on the side that users can tap to select a general region of the body. Tapping on these buttons navigates to a list of potential symptoms in and around the selected area. Furthermore, we learned that the patients may not be comfortable looking at those areas in pictures and therefore the body we designed was always fully clothed. An abstract body was suggested at first (see [Figure 1\(b\)](#)); however, a more realistic looking woman was suggested in future iterations (see [Figure 2\(a\)](#)).

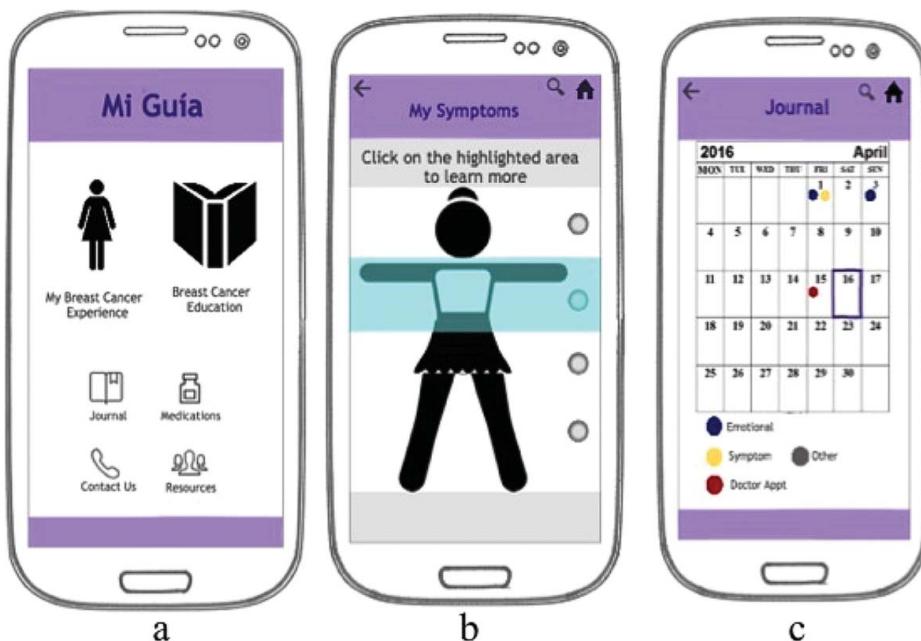


Figure 1. One of the early iteration of the Mi Guía prototype presented to community leaders and medical professionals. (a) The main screen, (b) the 'My Symptoms' subsection of 'My Breast Cancer Experience', (c) The Journal.

- (2) Our community leaders felt that the body of the more realistic looking woman used in the symptom checker was not representative of the norm in our target population. Community leaders recommended that the body

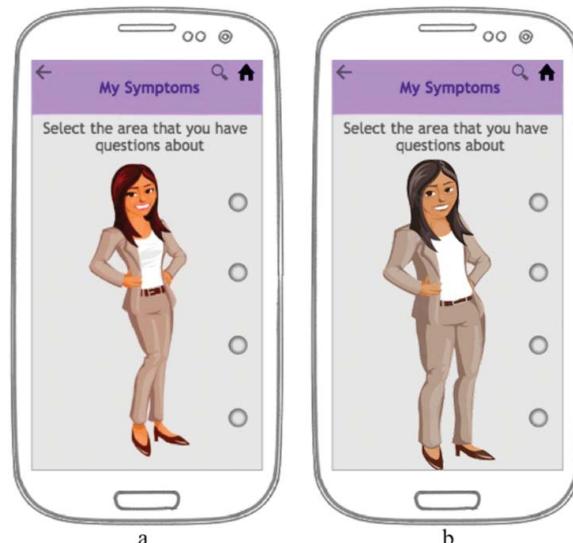


Figure 2. Woman cartoon featured in 'My Symptoms' prototype. (a) Initial version; (b) version after feedback.

be more normative (more athletic, older and less even breasts) as a figure that is not normative of our users may be intimidating and non-identifying for our target population (see [Figure 2\(b\)](#)).

- (3) Our community leaders suggested that we include the technical medical terminology followed by the word that the patients use to refer to it in parentheses. For example, our participants rarely used the name of one of the common breast cancer medications (Tamoxifen). Instead, they simply referred to it as 'the pill'. Another example is chemotherapy. Although there is a precise Spanish translation, patients often just refer to this as 'chemo'. Thus, we included these more colloquial terms in parentheses.
- (4) Other feedback referred to wording and slight reorganization of content. The 'My Breast Cancer Experience' section was sub-divided into three sections: (1) Symptoms related to emotional stability ('My Emotions'); (2) Symptoms related to corporal discomfort ('My Symptoms') and (3) Symptoms related to relationships ('My Family & Friends'). Lastly, an interactive component was added: A 'Myth or Fact' game to test the knowledge of the patients.

Heuristic evaluation of design principles

We evaluated numerous iterations of the application for adherence to design principles throughout the development of Mi Guía. In addition, before obtaining feedback from users, we conducted a more formal evaluation of Mi Guía based on widely accepted design principles. We trained 28 undergraduate students taking a human-computer interaction course at a Midwestern university to evaluate applications using the Nielsen's 10-point usability heuristics ([Nielsen 1994](#)). Although the heuristics are geared towards computer-based applications, in practice, most of these are applicable to mobile application design. The heuristics include items such as: consistency, conventions, and the ability to prevent and recover from errors.

Students were divided into nine groups. Each group was assigned four questions they needed to answer, such as 'What are the stages of breast cancer?' or 'Is cancer contagious?' The questions covered all areas of the application (see Appendix). Each question was answered by all students as they interacted with the system.

Furthermore, we asked the students to monitor and record the number of clicks it took them to find the answer, specifying the paths they tried. We computed the average number of steps it took to accomplish each task in order to determine which questions were easier and harder to answer. We also looked at improvements between the first task and the last task performed by a single group by assessing the number of clicks.

Results from heuristic evaluation

The hardest task for students was finding causes of lymphedema, which took 7.1 clicks. The easiest task was to locate the patient's next doctor's appointment (1.5

clicks). Most other tasks took somewhere between 3–4 clicks, except ‘Myth or Fact’ – a section we had included to be a fun trivia-like quiz – which turned out to be unclear as to the information contained in it. As expected, however, by the fourth task, the students were able to find their destination much more quickly. Some of the most significant violations to design principles found were: (1) lack of help (two mentions), (2) the journal section violated several consistency practices (six mentions) and (3) the Myth or Fact section did not serve a clear purpose (four mentions). In addition, the breakdown and wording of the main icons of the application and its sections were mentioned. However, the average severity of issues in the Nielsen heuristics scale was 2.2, which correspond to minor usability problems (those that are not a priority to fix).

The application was modified significantly after the Heuristic Evaluation session. Some revisions based on their feedback included a help menu and moving all the sub-sections of ‘My Breast Cancer Experience’ (‘My Emotions’, ‘My Symptoms’ and ‘My Family & Friends’) to the main screen ([Figure 3](#)). This, together with feedback from other groups of stakeholders at later iterations also resulted



Figure 3. Prototype version shown in usability tests with Latina breast cancer survivors: (a) Spanish version; (b) English version.

in the 'Myth or Fact' section being removed from the resulting application as it was not a place where users went to seek information.

Latina breast cancer survivors' feedback

After conducting the evaluation of design principles, we iteratively evaluated our prototype with nine Latina breast cancer survivors. The survivors were recruited through a cancer centre. The main eligibility criteria were: (1) identify as a Latina adult female; (2) had a diagnosis of breast cancer (stages I–IIIA) and (3) have completed active treatment at least six months before the interview.

The usability test occurred in four stages. First, the researcher explained the basic organization of the application to the participants. Second, participants were presented with 4–6 scenarios taken from the heuristic evaluation common to breast cancer survivors (e.g. 'My underarm is swollen, what could this be, and how can I manage it?') that covered the utilization of all sections of our prototype application (see Appendix). Because thinking aloud is a method that provides cognitive insights and elicits feedback the user may not otherwise give (Jaspers 2009), participants were told to think aloud, voicing their decisions and deliberations, as they interacted with the application to find the answers to these questions. Meanwhile, the researchers recorded the steps that participants took to find the answers, noting errors, corrections and suggestions. These individual sessions were audio recorded. Third, after they completed the scenarios presented, researchers asked participants to fill out a modified System Usability Scale (Brooke 1996) questionnaire. The survey was augmented with measures of attributes specific to mobile applications as detailed in the People At the Centre of Mobile Application Development (PACMAD) (Harrison, Flood, and Duce 2013) evaluation model. In particular, the survey captures self-reports of: satisfaction, memorability (degree to which the content is easy to remember), error rate (the degree to which tasks are completed correctly or the degree to which it is easy to go back and correct the error), learnability (the degree to which the system is easy to learn), effectiveness (the degree to which users can complete the task in a given context), efficiency (the degree to which users are able to efficiently complete a task accurately) and cognitive load (how well can users complete tasks in different settings). The questionnaire contained 23 items. These statements were translated into Spanish and read to the participants. The participants had to assess the degree to which they agreed with each statement using a Likert scale: 1 – not at all, 5 – completely. We found the explanations and oral responses to be necessary due to lower literacy rates of some of our users. Because social desirability introduced a risk for bias, if the participants only reported positive impressions of the application, the researchers read a script that encouraged criticism as being more useful than praise, and also took notes of some of their answers that clearly contrasted the participant's experience in the previous task. For example, we took note if they said that the application

was easy to use, but we saw them struggle with certain sections. Lastly, the researchers and patients would have a conversation about design proposals, feedback and general experience while using the prototype.

Results from usability testing

Of the nine users, one of the participants had a college degree, one had some college, three had a high school degree, one had some high school and three had less than or up to eighth grade. Of the five participants who disclosed their age, the average age was 59.2 years (the minimum was 40 and maximum 77). All but one reported using a smartphone several times a day. In addition, we administered a questionnaire to assess their knowledge about breast cancer prior to interacting with the prototype. Eight participants responded to the questionnaire and, as expected, their health literacy about breast cancer was low, with an average score of 9.3 ($SD = 2.4$) out of 16 points (58%).

While interviewing the users, we realized that these users have their own stories and expressed a desire to exchange stories and share experiences. Therefore, we decided to add quotes from these interviews directly into our application with permission, as well as stories gathered from other breast cancer support websites.

Other design feedback from user testing include:

- (1) Text sections and lists had too much content on it. While the material attempted to target a 6th grade reading level, the amount of content was a bit overwhelming for our participants. We therefore found that users were skimming the material without actually reading it. This leads to shorter lists with simpler, but still accurate language.
- (2) Many users commented on the purple colour and asked why it was not pink given that pink is the colour for breast cancer awareness for the breast cancer colour. This resulted in changing the colour scheme of the application to a pink theme.
- (3) Users had a lot of positive feedback about the app. The average response on the usability questionnaire was 4.23 out of a maximum of 5 ($SD = 0.9$). This average considers the reversed scores for some questions where higher scores denoted less favourable outcomes. Despite these high scores, we found surprising discrepancies. For example, although most women were in complete agreement with the statement: 'I found the application easy to use' ($M = 4.25$, $SD = 0.9$), we did not find a corresponding disagreement with statements like 'I needed to learn a lot of things before I could get going with this system' ($M = 2$, $SD = 2.0$) or 'I think that I would need the support of a technical person to be able to use this system' ($M = 3.0$, $SD = 1.82$). Based on this statement and our observations of patients' interactions with the application, we simplified lists to provide a quicker search of content, as we detected that was a frequent impediment to using the application efficiently.

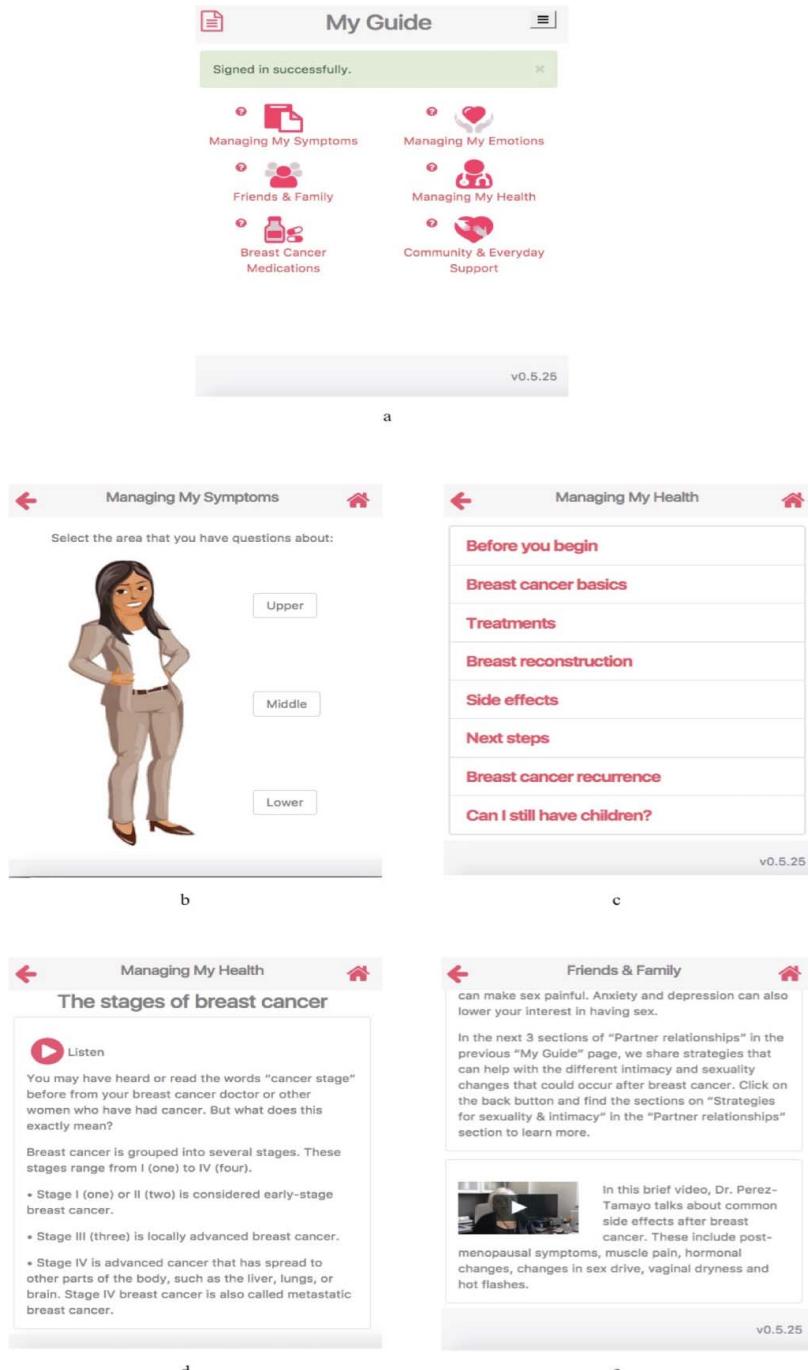
- (4) Many breast cancer survivors thought it would be a good idea to have audio-visual material to help with reading difficulties (e.g. low literacy) and to enable women to listen to the application while walking, etc. Therefore, the research team audio-recorded all of the written content in the application and embedded 'play' buttons throughout the application so that participants could listen to the application content. In addition, the oncologist that participated in the design team recorded videos that were embedded in to the application content. These videos focused on topics of relevance to breast cancer survivors (e.g. managing breast cancer treatment side effects, transitioning from treatment to survivorship).
- (5) We obtained significant feedback on the wording throughout the application. For example, one woman said that the word 'operation' should be used instead of 'surgery', another suggested that we stress that not every woman experiences the same – or any – of the side effects of hormonal therapy, and another suggested the application use a formal version of 'you' in Spanish ('Usted') consistently.

Resulting application

After several iterations with breast cancer survivors, community leaders, medical professionals and human-computer interaction professionals and students, we decided on the finalized look and feel of the application. In the end, it was determined that the application be developed as a web-based mobile application. This was in part driven by cost and to accommodate users with either Android or iOS devices more easily. In addition, section names were modified slightly to reflect actions. Time constraints, feedback from the heuristic evaluations and a final iteration with researchers and community leaders led to deleting the myth or fact section as well as the journal function and improving the section on community support. In addition, the wording and lists were simplified and subdivided into smaller lists. Lastly, every section with content was supplemented with a 'Play' button in order for the text to be read aloud. Furthermore, many sections now have videos to supplement the material (see [Figure 4](#) for the web-based mobile application).

Discussion on community-supported design and feasibility

In order to design *Mi Guía*, an mHealth application for Hispanic breast cancer survivors, we use a community-supported design approach, where we relied on community leaders, such as doctors and support group leaders, for prototype feedback in addition to users. Our community-supported approach merged participatory design (Kensing and Blomberg 1998) and user-centred design (Norman and Draper 1986) and added a strong community emphasis, where community leaders play a crucial role in the design process.



(a) Main Screen of Mi Guía:

Signed in successfully.

- Managing My Symptoms
- Managing My Emotions
- Friends & Family
- Managing My Health
- Breast Cancer Medications
- Community & Everyday Support

v0.5.25

(b) Managing My Symptoms:

Select the area that you have questions about:

Upper, Middle, Lower

(c) Managing My Health:

Before you begin

- Breast cancer basics
- Treatments
- Breast reconstruction
- Side effects
- Next steps
- Breast cancer recurrence
- Can I still have children?

v0.5.25

(d) Managing My Health - The stages of breast cancer:

Listen

You may have heard or read the words "cancer stage" before from your breast cancer doctor or other women who have had cancer. But what does this exactly mean?

Breast cancer is grouped into several stages. These stages range from I (one) to IV (four).

- Stage I (one) or II (two) is considered early-stage breast cancer.
- Stage III (three) is locally advanced breast cancer.
- Stage IV (four) is advanced cancer that has spread to other parts of the body, such as the liver, lungs, or brain. Stage IV breast cancer is also called metastatic breast cancer.

(e) Friends & Family:

In the next 3 sections of "Partner relationships" in the previous "My Guide" page, we share strategies that can help with the different intimacy and sexuality changes that could occur after breast cancer. Click on the back button and find the sections on "Strategies for sexuality & intimacy" in the "Partner relationships" section to learn more.

In this brief video, Dr. Perez-Tamayo talks about common side effects after breast cancer. These include post-menopausal symptoms, muscle pain, hormonal changes, changes in sex drive, vaginal dryness and hot flashes.

v0.5.25

Figure 4. Features implemented in the final iteration of Mi Guía, web-based mobile application, based on the feedback of community leaders, researchers and medical professionals. (a) Main Screen of Mi Guía; (b) simpler interaction with a more relatable cartoon; (c) shorter and simpler lists; (d) all content supports audio and (e) some content has embedded video.

Using feedback from community leaders, breast cancer survivors and a more formal heuristic evaluation, we were able to modify the content of Mi Guía to include appropriate language, colour and images, as well as stories, videos and audio. Furthermore, we reduced the amount of content in each section significantly.

Similar to Benson et al. (2016), we encountered anecdotal evidence of a response bias in our target population and participants tended to respond favourably. Therefore, we need to use caution when conducting user testing. For example, several users completely agreed with the statement ‘the application was easy to use’; however, at various points during some of the information finding tasks we noticed participants had difficulty completing them. In addition to careful observation during user testing, including community leaders who are able to be honest is a fundamental component in the design. For example, thanks to the contributions of community leaders, we were able to arrive at a satisfactory design of the cartoon figure in the ‘Managing My Symptoms’ section.

One of the main challenges of this approach is to reconcile feedback between stakeholders that may be contradictory. Researchers, community leaders, medical professionals and one patient (who is also a community leader) met several times as a large group to decide on contentious feedback. This approach can be expensive in terms of time, but we believe our community-supported approach resulted in an application that end users will benefit from.

Conclusion

In order to reduce disparities for Hispanic women with breast cancer who have limited cancer information, we designed Mi Guía (My Guide), a mobile web-based application that aims to improve symptom burden and HRQOL among Hispanic women with breast cancer. We use a community-supported design approach, where in addition to users, we obtained feedback from community leaders, such as support group organizers and facilitators as well as medical practitioners. This feedback helped us create an application which not only provides breast cancer information, but also provides an engaging way to interact with it, including audio, video and a symptom body checker. Finally, we believe this application is promising in great part due to the community-supported approach to its design.

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Disclosure statement

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References

- Aday, L. A., G. Y. Chiu, and R. Andersen. 1980. "Methodological Issues in Health Care Surveys of the Spanish Heritage Population." *American Journal of Public Health* 70 (4): 367–374.
- Almarri, Ayesha, and Tariq Bhatti. 2015. "Consumers Attitude towards the Use of Mobile Health Apps: An Empirical Review." In *The Second International Conference on Electrical and Electronics Engineering, Clean Energy and Green Computing (EEECEGC2015)*, 56–63. Konya, Turkey: Society of Digital Information and Wireless Communication at Melvana Universitesi.
- American Cancer Society. 2014. "Cancer Facts & Figures for Hispanics/Latinos 2012–2014." Accessed March 14 2018. <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-034778.pdf>.
- Atkinson, Nancy L., Sandra L. Saperstein, Sharon M. Desmond, Robert S. Gold, Amy S. Billing, and Jing Tian. 2009. "Rural eHealth Nutrition Education for Limited-Income Families: An Iterative and User-Centered Design Approach." *Journal of Medical Internet Research* 11 (2): e21. doi:10.2196/jmir.1148.
- Bender, Deborah E., Catherine Harbour, John Thorp, and Peter Morris. 2001. "Tell Me What You Mean by 'Sí': Perceptions of Quality of Prenatal Care Among Immigrant Latina Women." *Qualitative Health Research* 11 (6): 780–794. doi:10.1177/104973230101100607.
- Benson, Jemma, Emma Garrison, Jonathan Dropkin, and Paul L. Jenkins. 2016. "Methodological Concerns Related to Response Bias in Migrant and Seasonal Farmworkers." *American Journal of Industrial Medicine* 59 (12): 1112–1119. doi:10.1002/ajim.22646.
- Bickmore, Timothy W., Dina Utami, Robin Matsuyama, and Michael K. Paasche-Orlow. 2016. "Improving Access to Online Health Information with Conversational Agents: A Randomized Controlled Experiment." *Journal of Medical Internet Research* 18 (1): e1. doi:10.2196/jmir.5239.
- Brooke, John. 1996. "SUS – a Quick and Dirty Usability Scale." *Usability Evaluation in Industry* 189 (194): 4–7. doi:10.1002/hbm.20701.
- Byers, T. E., H. J. Wolf, K. R. Bauer, S. Bolick-Aldrich, V. W. Chen, J. L. Finch, J. P. Fulton, et al. 2008. "The Impact of Socioeconomic Status on Survival after Cancer in the United States : Findings from the National Program of Cancer Registries Patterns of Care Study." *Cancer* 113 (3): 582–591. doi:10.1002/cncr.23567.
- Cafazzo, Joseph A., Mark Casselman, Nathaniel Hamming, Debra K. Katzman, and Mark R. Palmer. 2012. "Design of an mHealth App for the Self-Management of Adolescent Type 1 Diabetes: A Pilot Study." *Journal of Medical Internet Research* 14 (3) e70: doi:10.2196/jmir.2058.

- De Vito Dabbs, Annette, Brad A. Myers, Kenneth R. Mc Curry, Jacqueline Dunbar-Jacob, Robert P. Hawkins, Alex Begey, and Mary Amanda Dew. 2009. "User-Centered Design and Interactive Health Technologies for Patients." *Computers, Informatics, Nursing : CIN* 27 (3): 175–183. doi:10.1097/NCN.0b013e31819f7c7c.
- Eysenbach, Gunther, and CONSORT-EHEALTH Group. 2011. "CONSORT-EHEALTH: Improving and Standardizing Evaluation Reports of Web-Based and Mobile Health Interventions." *Journal of Medical Internet Research* 13 (4): e126. doi:10.2196/jmir.1923.
- Fox, Susannah, and Maeve Duggan. 2012. *Mobile Health 2012*. Washington, DC: Pew Internet.
- Frascara, Jorge. 2002. "Summary for Policymakers." In *Climate Change 2013 - The Physical Science Basis*, edited by Intergovernmental Panel on Climate Change, 1–30. Cambridge: Cambridge University Press. <https://doi.org/10.1017/CBO9781107415324.004>.
- Fu, Mei R., Deborah Axelrod, Amber A. Guth, Kavita Rampertaap, Nardin El-Shammaa, Karen Hiotis, Joan Scagliola, Gary Yu, and Yao Wang. 2016. "mHealth Self-Care Interventions: Managing Symptoms Following Breast Cancer Treatment." *mHealth* 2 (July). 28–28. doi:10.21037/mhealth.2016.07.03.
- Fu, Olivia S., Katherine D. Crew, Judith S. Jacobson, Heather Greenlee, Gary Yu, Julie Campbell, Yvette Ortiz, and Dawn L. Hershman. 2009. "Ethnicity and Persistent Symptom Burden in Breast Cancer Survivors." *Journal of Cancer Survivorship : Research and Practice* 3 (4): 241–250. doi:10.1007/s11764-009-0100-7.
- Gilbertson-White, Stephanie, Chi Yeung, Keri Nace Mercer, Dorota Bartoczyk, and Todd Papke. 2016. "Developing an eHealth Intervention for Cancer Symptom Management for Rural Residents." *Journal of Clinical Oncology* 34 (26_suppl): 207. https://doi.org/10.1200/jco.2016.34.26_suppl.207.
- Harrison, Rachel, Derek Flood, and David Duce. 2013. "Usability of Mobile Applications: Literature Review and Rationale for a New Usability Model." *Journal of Interaction Science* 1 (1): 1–16. doi:10.1186/2194-0827-1-1.
- Hopwood, Christopher J., Claudia G. Flato, Suman Ambwani, Beth H. Garland, and Leslie C. Morey. 2009. "A Comparison of Latino and Anglo Socially Desirable Responding." *Journal of Clinical Psychology* 65 (7): 769–780. doi:10.1002/jclp.20584.
- Jaspers, Monique W. M. 2009. "A Comparison of Usability Methods for Testing Interactive Health Technologies: Methodological Aspects and Empirical Evidence." *International Journal of Medical Informatics* 78 (5): 340–353. doi:10.1016/j.ijmedinf.2008.10.002.
- Jibb, Lindsay A., Bonnie J. Stevens, Paul C. Nathan, Emily Seto, Joseph A. Cafazzo, and Jennifer N. Stinson. 2014. "A Smartphone-Based Pain Management App for Adolescents with Cancer: Establishing System Requirements and a Pain Care Algorithm Based on Literature Review, Interviews, and Consensus." *JMIR Research Protocols* 3 (1): e15. <https://doi.org/10.2196/resprot.3041>.
- Kagawa-Singer, M., A. Valdez Dadia, M. C. Yu, and A. Surbone. 2010. "Cancer, Culture, and Health Disparities: Time to Chart a New Course?" *CA: A Cancer Journal for Clinicians* 60 (1): 12–39. doi:10.3322/caac.20051.
- Kensing, Finn, and Jeanette Blomberg. 1998. "Participatory Design: Issues and Concerns." *Computer Supported Cooperative Work (CSCW)* 7 (3–4): 167–185. doi:10.1023/A:1008689307411.
- Leykin, Yan, Seema M. Thekdi, Dianne M. Shumay, Ricardo F. Muñoz, Michelle Riba, and Laura B. Dunn. 2012. "Internet Interventions for Improving Psychological Well-Being in Psycho-Oncology: Review and Recommendations." *Psycho-Oncology* 21 (9): 1016–1025. <https://doi.org/10.1002/pon.1993>.
- Lopez, Mark Hugo, Ana Gonzalez-Barrera, and Eileen Patten. 2013. "Closing the Digital Divide: Latinos and Technology Adoption." *Pew Hispanic Center*. Accessed December 12 2017. <http://www.pewhispanic.org/2013/03/07/closing-the-digital-divide-latinos-and-technology-adoption/>.

- Luckett, Tim, David Goldstein, Phyllis N. Butow, Val Gebski, Lynley J. Aldridge, Joshua McGrane, Weng Ng, and Madeleine T. King. 2011. "Psychological Morbidity and Quality of Life of Ethnic Minority Patients with Cancer: A Systematic Review and Meta-Analysis." *The Lancet Oncology* 12 (13): 1240–1248. doi:10.1016/S1470-2045(11)70212-1.
- Martin, Thomas. 2012. "Assessing mHealth: Opportunities and Barriers to Patient Engagement." *Journal of Health Care for the Poor and Underserved* 23 (3): 935–941. doi:10.1353/hpu.2012.0087.
- McCurdie, Tara, Svetlena Taneva, Mark Casselman, Melanie Yeung, Cassie McDaniel, Wayne Ho, and Joseph Cafazzo. 2012. "mHealth Consumer Apps: The Case for User-Centered Design." *Biomedical Instrumentation & Technology/Association for the Advancement of Medical Instrumentation* 46 (Suppl): 49–56. doi:10.2345/0899-8205-46.s2.49.
- Mirkovic, Jelena, David R. Kaufman, and Cornelia M. Ruland. 2014. "Supporting Cancer Patients in Illness Management: Usability Evaluation of a Mobile App." *Journal of Medical Internet Research* 16 (8): e33. <https://doi.org/10.2196/mhealth.3359>.
- Mohr, David C., Stephen M. Schueller, Enid Montague, Michelle Nicole Burns, and Parisa Rashidi. 2014. "The Behavioral Intervention Technology Model: An Integrated Conceptual and Technological Framework for eHealth and mHealth Interventions." *Journal of Medical Internet Research* 16 (6): e146. doi:10.2196/jmir.3077.
- Molina, Yamile, Beti Thompson, Noah Espinoza, and Rachel Ceballos. 2013. "Breast Cancer Interventions Serving US-Based Latinas: Current Approaches and Directions." *Women's Health* 9 (4): 335–350. doi:10.2217/whe.13.30.
- Nielsen, Jakob. 1994. "Heuristic Evaluation." In *Usability Inspection Methods*, edited by Jakob Nielsen and Robert L. Mack, 1st ed, 25–62. New York: Wiley.
- Norman, Donald A., and Stephen W. Draper. 1986. User Centered System Design. New Perspectives on Human-Computer Interaction. Hillsdale, NJ: Lawrence Erlbaum.
- Pandey, Ambarish, Sayeedul Hasan, Divyanshu Dubey, and Sasmit Sarangi. 2013. "Smartphone Apps as a Source of Cancer Information: Changing Trends in Health Information-Seeking Behavior." *Journal of Cancer Education* 28 (1): 138–142. doi:10.1007/s13187-012-0446-9.
- Penedo, Frank J., Lara Traeger, Jason Dahn, Ivan Molton, Jeffrey S. Gonzalez, Neil Schneiderman, and Michael H. Antoni. 2007. "Cognitive Behavioral Stress Management Intervention Improves Quality of Life in Spanish Monolingual Hispanic Men Treated for Localized Prostate Cancer: Results of a Randomized Controlled Trial." *International Journal of Behavioral Medicine* 14 (3): 164–172. doi:10.1007/BF03000188.
- Reay, Stephen D., Guy Collier, Reid Douglas, Nick Hayes, Ivana Nakarada-Kordic, Anil Nair, and Justin Kennedy-Good. 2017. "Prototyping Collaborative Relationships between Design and Healthcare Experts: Mapping the Patient Journey." *Design for Health* 1 (1): 65–79. doi:10.1080/24735132.2017.1294845.
- Saint-Germain, Michelle A., Tamsen L. Bassford, and Gail Montano. 1993. "Surveys and Focus Groups in Health Research with Older Hispanic Women." *Qualitative Health Research* 3 (3): 341–367. doi:10.1177/104973239300300306.
- Sanders, Elizabeth B.-N., and Pieter Jan Stappers. 2008. "Co-Creation and the New Landscapes of Design." *CoDesign* 4 (1): 5–18. doi:10.1080/15710880701875068.
- Schouten, Barbara C., and Ludwien Meeuwesen. 2006. "Cultural Differences in Medical Communication: A Review of the Literature." *Patient Education and Counseling* 64 (1–3): 21–34. doi:10.1016/j.pec.2005.11.014.
- Steele Gray, Carolyn, Daniel Miller, Kerry Kuluski, and Cheryl Cott. 2014. "Tying eHealth Tools to Patient Needs: Exploring the Use of eHealth for Community-Dwelling Patients with Complex Chronic Disease and Disability." *JMIR Research Protocols* 3 (4): e67. doi:10.2196/resprot.3500.

- Van Velsen, Lex, Jobke Wentzel, and Julia E. W. C. Van Gemert-Pijnen. 2013. "Designing eHealth That Matters via a Multidisciplinary Requirements Development Approach." *JMIR Research Protocols* 2 (1): e21. <https://doi.org/10.2196/resprot.2547>.
- Wilson, Elisabeth, Alice Hm Chen, Kevin Grumbach, Frances Wang, and Alicia Fernandez. 2005. "Effects of Limited English Proficiency and Physician Language on Health Care Comprehension." *Journal of General Internal Medicine* 20 (9): 800–806. doi:10.1111/j.1525-1497.2005.0174.x.
- Yanez, Betina, Heather L. McGinty, David C. Mohr, Mark J. Begale, Jason R. Dahn, Sarah C. Flury, Kent T. Perry, and Frank J. Penedo. 2015. "Feasibility, Acceptability, and Preliminary Efficacy of a Technology-Assisted Psychosocial Intervention for Racially Diverse Men with Advanced Prostate Cancer." *Cancer* 121 (24): 4407–4415. doi:10.1002/cncr.29658.
- Yanez, Betina, Annette L. Stanton, and Rose C. Maly. 2012. "Breast Cancer Treatment Decision Making among Latinas and Non-Latina Whites: A Communication Model Predicting Decisional Outcomes and Quality of Life." *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association* 31 (5): 552–561. doi:10.1037/a0028629.
- Yanez, B. E. H. Thompson, and A. L. Stanton. 2011. "Quality of Life Among Latina Breast Cancer Patients: A Systematic Review of the Literature." *Journal of Cancer Survivorship* 5 (2): 191–207. doi:10.1007/s11764-011-0171-0.
- Zapata, Belén Cruz, José Luis Fernández-Alemán, Ali Idri, and Ambrosio Toval. 2015. "Empirical Studies on Usability of mHealth Apps: A Systematic Literature Review." *Journal of Medical Systems* 39 (2): 1–19. doi:10.1007/s10916-014-0182-2.

Appendix

Questions that participants had to answer using the prototype of the application:

- (1) My underarms are swollen, why can that be? How do I prevent it?
- (2) I am feeling sad sometimes, sometimes I cry, and sometimes I am cranky. Why is this?
- (3) Tamoxifen is a common medication for breast cancer survivors. Do all patients experience the same side effects? What are they?
- (4) When's my next doctor's appointment?
- (5) What are the stages of breast cancer?
- (6) Is cancer contagious?
- (7) Besides this app where else can I get support?
- (8) My chest is hard today. How can I record this information?
- (9) Is it true that cancer is a death sentence?
- (10) My chest is hard? Why is that?
- (11) How long ago did you last feel depressed?
- (12) What are the long term side effects of a mastectomy?